

Questionnaire: What Are My Goals of Care?

1. What is my current understanding of where I am with my illness? (*What have you heard already from your health care team? What have you learned from the internet or friends and family? What is your current understanding of what is happening to your body?*)
2. What has the doctor communicated with me so far? (*Has the doctor actually shared a prognosis or what is likely to happen? Have they communicated the kind of therapeutic options that are part of their plan of care?*)
3. How much more information about my current condition and future prognosis would I like to have? What do I want to know? What do I need to know? (*In some cultures, a patient is never told what is happening; information is only shared with a point person, such as the eldest child in the family, who then decides what the patient needs to know. What are your cultural beliefs about knowing and sharing difficult information?*)
4. What are my biggest fears and worries? (*Are you scared that you won't be able to care for others [children or a spouse] physically or financially? Are you scared to lose control? Are you frightened of being in pain or suffering physically? Are you worried about being a burden or lingering too long?*)
5. What gives me strength as I think about the future and my health concerns or illness? (*Is it your family or friends, faith or religion, a support group, or specific activities, like travel, reading, writing, gardening, or socializing with family and friends?*)

6. Which abilities are so critical to my life that I cannot imagine living without them? *(Is it being able to communicate with others? Are they walking, driving, and living at home alone? Is it taking care of your activities of daily living [ADLs] such as feeding, toileting, and dressing yourself?)*
7. If my health situation worsens, what's most important to me? *(Do you want to achieve an important life goal that you have not yet accomplished? Is it important for you to have mental awareness above all else? Do you want to do all you can to protect and support your family? Is it most important for you to be at home as long as possible, be physically comfortable as long as possible, or to be independent?)*
8. If I become sicker, how much am I willing to go through for the possibility of gaining more time? *(Do you want to avoid some procedures or treatments if their benefit is not substantial? Are you willing to be on a ventilator, live in a nursing home, endure physical discomfort or severe pain, spend time in the ICU, undergo invasive tests or procedures, or have a feeding tube?)*
9. How much does my health care proxy/durable power of attorney agent (see pages 77–80) or family know about my wishes and priorities?